

**National Workshop on
Achieving Equity in Genetics Policy
through Diversity in Decision Making**

Co-Sponsored By:

Life Sciences & Society Program and the Center for Public Health and Community Genomics
at the University of Michigan

In Collaboration With

The National Human Genome Center, Howard University
The Joint Center for Political and Economic Studies, Health Policy Institute

FINAL REPORT

Executive Summary

Advances in genomic research and technologies carry hope for the dramatic reduction of disease, and there is little doubt that many of these hopes will become reality. What is not so clear is whether these advances will be applied equally across society and the extent to which the new information derived from genetic advances will be used to reduce rather than increase health disparities. In response to this concern, and to the need for decision-making processes inclusive and reflective of the interests of our diverse society the **Genetics Equity Network** was launched in October 5th 2006 at the **National Workshop on Achieving Equity in Genetics Policy through Diversity in Decision Making**, an event funded by the University of Michigan's National Center for Institutional Diversity, and sponsored by the Life Sciences & Society Program and Center for Public Health and Community Genomics at the University of Michigan in collaboration with Howard University's National Human Genome Center and the Health Policy Institute.

The workshop was attended by forty-two individuals representing a diverse set of 32 organizations which work on health disparities issues in communities, policy, and research. Thirty-five additional organizations, whose representatives were unable to attend, have also indicated their desire to participate in the Network.

Community-based, policy, and research organizations with a primary interest in health disparities were invited to attend the workshop and to consider the role of genetics in their shared mission of reducing health disparities. The day-long workshop, facilitated by Dr. David Campt, began by providing general information to pique interest in genetics, health disparities, and policy. During discussion sessions in the afternoon, we drew from the diverse experience in the room and discussed the lessons-learned in forming other networks (i.e., what works, what doesn't work), possible areas for development within this network, and the sustainability of the network over time. At the end of the day, we launched the Network's website: <http://www.geneticsequitynetwork.org> at a reception following the workshop.

Since its inception, the Network has continued to become stronger, and has come together to provide feedback to members of Congress on a variety of genetics policies.

Purpose

On October 5th 2006 the **Genetics Equity Network** was launched at the **National Workshop on Achieving Equity in Genetics Policy through Diversity in Decision Making**, an event funded by the University of Michigan's National Center for Institutional Diversity. This event focused on strategies for turning genetics-related issue areas into action plans. Primary discussion areas included how genetics, racial/ethnic health disparities, and policy are inter-related, and how best to work in the policy arena to move toward the elimination of health disparities and the improvement of health for all. The workshop was attended by forty-two individuals representing a diverse set of 32 organizations which work on health disparities issues in communities, policy, and research. 35 additional organizations, whose representatives were unable to attend, have also indicated their desire to participate in the Network.

The purpose of launching the **Genetics Equity Network** at the Workshop was to assure that the ideas shared at the event would be turned into action. Such an alliance of diverse groups is essential amid the explosion of genetic knowledge and technology that influences research and health care. How this information is managed, who decides what and how to study genetics, and which technologies to develop for whom, are all key questions as their answers have powerful and meaningful implications.

Over the last decade, the Human Genome Project has stimulated an avalanche of genetics research that is consuming approximately 20% of NIH's annual budget. Francis Collins and the National Human Genome Research Institute are currently lobbying congress to raise 3 to 4 billion dollars to conduct a one million person cohort study on the genetic factors and gene-environment interactions that underlie common chronic diseases in the United States. Newborn genetic screening policies and adult genetic screening policies are expanding in scope yearly.

Not only are genetic screening policies expanding, but a variety of genetic policies are evolving and expanding rapidly, developed by federal and state government agencies, legislatures and Congress, private and public sources of funding for healthcare, and by corporations in developing and marketing genetics technologies. The leaders of these organizations are overwhelmingly homogeneous and reflect the relatively advantaged in society. Influencing this policy process are special interest groups and industry representatives that speak for those with rare genetic disorders or those in biotechnology who have a stake in the business of genetic advances and technology. Like the policymakers themselves, the leadership in these interest groups is likewise overwhelmingly homogenous and the relatively advantaged in society.

Advances in genomic research and technologies carry hope for the dramatic reduction of disease, especially chronic diseases and others traditionally detected through Newborn Screening Programs. There is little doubt that many of these hopes will become reality. What is not so clear, however, is whether these advances will be applied equally across society and the extent to which the new information derived from genetic advances will be used to reduce rather than increase disparities.

Diversity in the decision making processes of the institutions that define genetic policies is paramount to assuring fair application of advances, and is a necessary precondition to the application of genetics toward the reduction, and eventual elimination, of health disparities. Because the proliferation of genetic advances and policies is imminent, sustainable engagement of institutional leaders, especially community leaders who have been left out of decision making processes to date, is essential. Unless we achieve a more diverse representation of society to participate in genetic policy making we are

likely to repeat the troubled history of public health genetics –e.g. the sickle cell screening of the 1970's that increased genetic discrimination and stimulated the creation of marriage laws in two-thirds of the United States, or a repeat of the history of eugenics that applied distorted views of inherited traits to the development of policies harmful to non-whites and other minorities.

Event Goals

Goal 1: *Stimulate interactions among leadership of key organizations committed to reducing health disparities*

The Steering Committee was comprised of the directors of the four sponsoring agencies as well as their staff. The Committee met 1 -2 times per month from May 2006 until the date of the workshop, October 5th to plan the agenda, identify speakers, and an invitation list. One of the first decisions was that we would invite community-based, policy, and research organizations with a primary interest in health disparities, and invite them to consider the role of genetics in their shared mission of reducing health disparities.

Invitations to the workshop were extended to organizations previously identified by the Poverty and Race Research Action Council (PRRAC) as working in the area of health disparities. Also approached were representatives in the Congressional Black Caucus and Hispanic Caucus, and the leadership of the National Community Committee (NCC), which represents the community-based organizations that work on issues of health disparities and are affiliated with CDC-funded Prevention Research Centers. While a majority of invitations were extended to organizations in the Washington D.C. area, we were able to provide travel scholarships to NCC leaders and the West Harlem Environmental Action Council (WE ACT). Organizations represented at the workshop included the Association of State and Territorial Health Officers, NIH's National Human Genome Research Institute, National Health Law Program, and Families USA. Staff members from the Offices of Senator Kennedy and Representative Edolphus Towns attended, as did the past and current presidents and president-elect of the NCC.

Potential participants received two mailings, and a phone call. In the initial packet of material, invitees received a survey to indicate their main areas of interest, as well as information from the popular media or developed in-house that explained the potential impact on health disparities of race-based medicine, genetic discrimination in the workplace, the impact of genetic testing on health insurance policy, and the current research plans for a ~\$3 billion study of gene-environment interactions that would involve as many as 500,000 individuals. We also developed a brochure that was mailed out during the Summer 2006. Because genetics was a new area for many of these organizations, subsequent phone contact helped in recruitment and in identifying areas of interest so the workshop could be tailored to the audience.

The list of Steering Committee members, brochure, and a full participant list are attached (Attachments 1, 2, and 3). Attachment 4 contains a list of all organizations who have indicated their desire to participate in the Network, whether or not they participated in the workshop.

Goal 2: *Share knowledge of how decisions are currently made by institutions shaping genetics policies*

The day-long workshop, facilitated by Dr. David Campt, was designed to provide general information and pique interest in genetics, health disparities, and policy, during the morning session. The final agenda is available as Attachment 5. Sharon Kardia, PhD,

of the University of Michigan presented on the link between genetics, environment, and health disparities. Marcel Welty, National Council of Churches, Vence Bonham, National Human Genome Research Institute, and Gail Christopher, Health Policy Institute, co-presented on policy issues at the intersection of genetics and health disparities. Aranthan Jones, Chief of Staff for Congressman William Jefferson of the 2nd-District of Louisiana, had been scheduled to speak on this topic, however he was unable to appear due to a last minute conflict. Makani Themba-Nixon, Executive Director of the Praxis Project spoke about how communities can become involved in the policy process and in actively changing current policies. Biographies provided to workshop attendees are provided as Attachment 6.

This unique combination of research, community advocacy, and policy expertise stimulated ideas and conversation. As the evaluation report (Attachment 7) suggests, these presentations carried the dialogue throughout the day, especially Dr. Kardia's.

Goal 3: *Consider strategies that will enable a more diverse group of stakeholders to develop meaningful roles in shaping these policies*

In the first of two afternoon sessions, we drew from the diverse experience in the room and discussed what the lessons have been in forming other networks (i.e., what works, what doesn't work). Two main themes came out of this session: First, practically speaking, a network needs some structure and resources. For example, funding and staff time, training, and a listserv. On the other hand, over-reliance on technology for communication and time limitations are classic pitfalls. Second, according to the group, network needs an environment conducive to growth and development: Good communication, evaluation, inclusivity. Exclusion, and "worthy but unrealistic goals" are detrimental.

Also during this part of the event, participants were polled on their primary areas of interest for the Network. These were:

- Current genetic anti-discriminatory legislation
- Racial categories in genetics research
- Participation in genetics research
- Informed consent issues
- Access to genetics health care
- The biotech industry and patenting
- Health information technology
- Community genetics education
- Participation in genetic research; identifiability in large databases
- Environmental justice
- Message framing

Receiving the most votes were education, and genetic anti-discrimination legislation. Also high on the agenda for the group, were participation in genetics research, and message framing. Participants were asked to select a topic of interest to discuss one of these four issues, or the question of sustainability in small group discussion.

Interestingly, most people were drawn to internally, rather than externally, focused questions. Despite being high on the interest poll, Genetic Discrimination Legislation had no group members, while the largest groups discussed education, participation in genetics research, and message framing. While there was no small group discussion of sustainability, this was addressed as a larger group.

The group discussions provided valuable feedback on how we conceive of this network; for example, we were encouraged to facilitate networking by sharing information about the member organizations, communicate via both electronic methods and “regular old mail.” Other suggestions included articulating a set of values that we share that would guide the development of the field of genetics, education, and maintaining a sense that the Network is essentially a “fuzzy institution” wherein the overall mission would reflect broad values that many organizations can agree upon, but allows for activity among sub-groups interested in common topics to come together on policy issues as they arise.

The notes from the afternoon discussions have been typed up, and are provided as Attachment 8.

Goal 4: *Develop an action plan to implement these strategies*

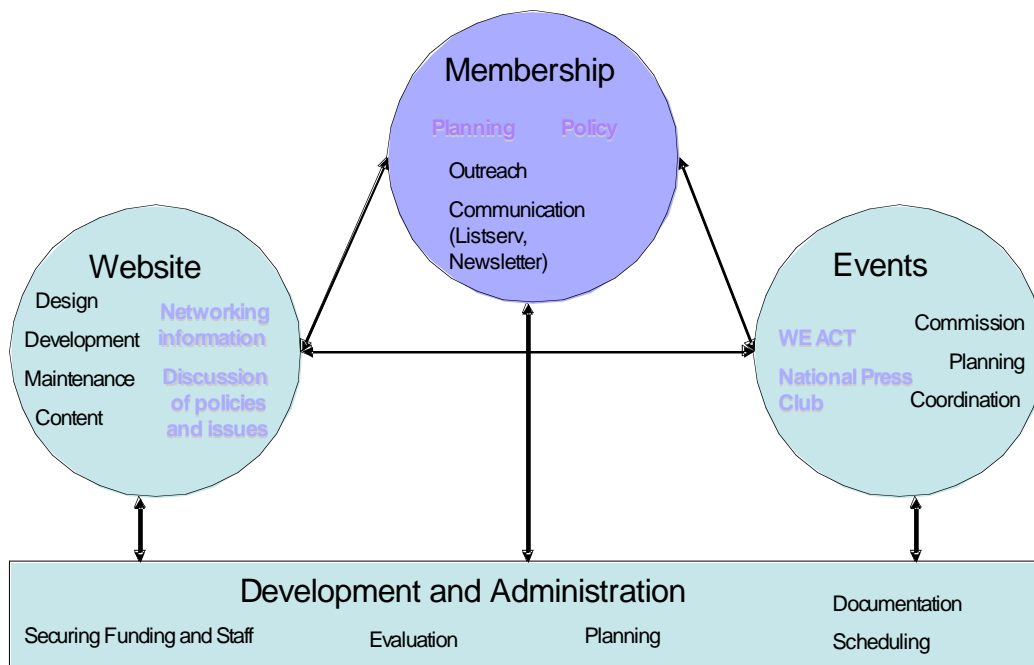
At the end of the day, we launched the website that will support the activities of the Network: <http://www.geneticsequitynetwork.org> (See Attachment 9). The website provides education resources and information about the Network. It will also host recordings of the recorded morning speakers. We are currently developing a plan for further development of the website to include interactive elements that will assist in collaboration, networking, and the development, comment, and advocacy of policies.

We have also further refined a listserv that is active in commenting on a variety of policies. The Network provided feedback on a bill that is yet to be introduced by Senator Kennedy that would regulate genetic tests to assure clinical and analytical validity. The Network is currently working on creating a statement on the recently introduced Genetic Information Non-Discrimination Act. Considering the desire for multiple channels of communication, we have held conference calls to stimulate discussion and use the telephone to keep in touch with members in addition to the communication via email.

Beginning in February 2007, we will be holding a regular meeting among members of the Network to identify issue areas, activities, and priorities for the year. The Steering Committee continues to meet to strategize for the continued success of the Network. The Genetics Equity Network will be a resource for the Midwest Community Genetics Forums that will be held this year through a grant awarded by NIH's National Human Genome Research Institute by serving as forum for discussion of the policy implications of genetic research agendas. Figure 1 (below) depicts the relationship between the activities of the Network and demonstrates the partnership between members and the Steering Committee, which originally conceived of this project. The Life Sciences & Society Program and Center for Public Health and Community Genomics at the University of Michigan, the Joint Center for Political and Economic Studies Health Policy Institute, and our partners at Howard University are also committed to furthering the success of the Network through the provision of funds and staff time.

Figure 1.

The Genetics Equity Network



KEY
Members
Steering
Committee

ATTACHMENTS

Attachment 1.....	Steering Committee
Attachment 2.....	Brochure
Attachment 3.....	Final participant list
Attachment 4.....	Genetics Equity Network member organizations
Attachment 5.....	Agenda
Attachment 6.....	Biographies
Attachment 7.....	Evaluation report
Attachment 8.....	Group discussions notes
Attachment 9.....	Website
Attachment 10.....	Final budget

Attachment 1 – Steering Committee

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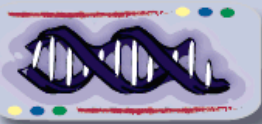
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Attachment 2 - Brochure

The Genetics Equity Network



ACHIEVING
Equity in Genetics Policy
through Diversity in
Decision Making

The increasing ability to connect DNA variation with non-medical conditions such as personality traits or intelligence, will challenge our society. We will need to be constantly vigilant in opposing a creeping deterministic view that denies the critical role of the environment, freedom of opportunity and free will.

- Francis Collins, National Human Genome Research Institute, NIH

The problem is not that issues of individual autonomy, genetic discrimination, genetic confidentiality, intellectual property, patent rights, informed consent, and the like raise difficult ethical, moral, and legal questions. Problems most often rise from differences in the way different individuals, groups and cultures respond to and resolve problems.

- Georgia Dunston, Howard University

The human genome underlines the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.
- United Nations Educational, Scientific and Cultural Organization (UNESCO)

The Day's Agenda

October 5, 2006
8:30 a.m. - 3:30 p.m.
reception to follow

Howard University Research Building
(HURB1)
1840 7th Street
Washington, D.C. 20001

MAKING CONNECTIONS APPLYING CONCEPTS

Through a moderated panel discussion and group dialogue, David Campt, PhD will lead us through discovery and deliberation of these questions

- How is genetics related to racial and ethnic health disparities?
- How might diversity in genetics policy-making reduce health disparities?
- Why do we need to engage our communities?

STARTING TODAY

During a working lunch, we will work in smaller groups through facilitated discussion of how our communities can reduce barriers in creating, reviewing, and advocating policy around genetics research, public health, and

MOVING TOWARD ACTION

In the day's final session, we will work together to look ahead to making this more than just another workshop:

- How will we create supportive connections within the Genetics Equity Network to maintain a sustainable and diverse partnership?
- What kinds of activities do we envision as central to the Network?
- How can we position the strength of our relationships to secure funds and other resources to increase and sustain diversity at the genetics policy tables?

LAUNCHING THE NETWORK

A reception will follow to officially launch the Network and will feature the website we are creating to support the Network.



ISSUES IN GENETICS & RACIAL/ETHNIC HEALTH DISPARITIES

These are just a few examples of policy issues that bridge genetics and health disparities.

CRIMINAL JUSTICE

DNA Databases are used increasingly in the criminal justice system without question as to social meaning or scientific reliability.

ACCESS TO HEALTH

Developing expensive technologies based on genetics can widen disparities if universal (public and private) access is not achieved.

RACE-BASED MEDICINE

Race-based pharmaceutical marketing (e.g. BiDil) may exacerbate stigmatization and discrimination.

RESEARCH

Public and private agencies spend billions of dollars on genetics research. Is it adequately contributing to the reduction of health disparities?

EDUCATION & THE DIGITAL DIVIDE

Differences in who knows about genetics and genetic technology has implications for who has access.



THIS WORKSHOP IS BEING SPONSORED BY:

Howard University's National Human Genome Center
The Joint Center for Political and Economic Studies:
Health Policy Institute
The Michigan Center for Genomics and Public Health
The Life Sciences and Society Program and the
National Center for Institutional Diversity at the

NATIONAL WORKSHOP ON ACHIEVING EQUITY IN GENETICS POLICY THROUGH DIVERSITY IN DECISION MAKING

This event will focus on strategies for turning issue areas into action plans. We will discuss how genetics, racial/ethnic health disparities, and policy are interrelated, and how best to work in the policy arena to move toward the elimination of health disparities and the improvement of health for all. Attending the workshop will be a diverse set of organizations with varying degrees of experience in genetics, who work in our communities, policy, research, and the media.

THE GENETICS EQUITY NETWORK

(tentatively named)

The formation of a network to assure that our ideas are turned into action is one of the goals of this workshop. Such an alliance is essential amid the explosion of genetic knowledge and technology that influences research and health care. How this information is managed, who decides what and how to study genetics, and which technologies to develop for whom, are all key questions as their answers have powerful and meaningful implications.

LOCATION AND TIME

The workshop will be held on Thursday, October 5th, 2006 from 8:30 a.m. - 3:30 p.m. with a reception to follow at the Howard University Research Building (HURB1), 1840 7th Street, Washington, DC 20001.

HOW TO REGISTER

Registration is free, but we ask that you please respond with your intent to attend the workshop to Sally Meyer at the Michigan Center for Genomics and Public Health (MCGPH): 734-615-3412; salmeyer@umich.edu

QUESTIONS?

We are always happy to speak with you and can be reached through the MCGPH, Sally Meyer, 734-615-3412, salmeyer@umich.edu



E SCIENCES & SOCIETY

University of Michigan

School of Public Health

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Ann Arbor, Michigan 48104-3028

You are Invited



*On October 5th, Come Launch
the Genetics Equity Network at
the National Workshop on
Achieving Equity in Genetics
Policy through Diversity in*

Attachment 3 – Final Participant List

The Genetics Equity Network:

Achieving Equity In Genetics Policy thru Diversity in Decision Making 10/5/06 PARTICIPANTS

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Attachment 4 – Genetics Equity Network Member Organizations

African American Health Alliance (AAHA) Washington, DC	American Civil Liberties Union Racial Justice Working Group New York, NY	American Federation of Government Employees, AFL-CIO Washington, DC
Norm Anderson American Psychological Association (APA) Washington, DC	Andrew Austin-Dailey American Psychological Association (APA), Minority Fellowship Program Washington, DC	American Psychological Association (APA) Office of Ethnic Minority Affairs Washington, DC
American Psychological Association Washington, DC	Asian & Pacific Islander American Health Forum Washington, DC	ASPIRA Association Washington, DC
Association of State & Territorial Health Officials Washington, DC	Center for Environment, Commerce, and Energy Washington, DC	Center for Health, Environment, and Justice Falls Church, VA
Center for Policy Alternatives, Washington, DC	Children's Environmental Health Network Washington, DC	Columbia Heights/Shaw Family Support Collaborative Washington, DC
C. Gillespie Congressional Black Caucus Foundation, Inc. Washington, DC	Coordinating Council of Muslim Organizations (CCMO) Herndon, VA	Council on American-Islamic Relations (CAIR) Washington, DC

DC Genealogy Society
Clinton, MD

Families USA
Washington, DC

Genetic Alliance
Washington, DC

Genetics and Public Policy Center
Washington , DC

George Washington University Law School
Washington, DC

Committee on Health, Education, Labor & Pensions/Senator Edward M. Kennedy
Washington, DC

Health Liaison to Senator Barak Obama
Washington , DC

Health Liaison to Rep. Donna Christensen
Washington, DC

Howard University National Human Genome Center
Washington, DC

Institute of Social Medicine and Community Health,
Washington, DC

Jacobs Institute of Women's Health
Washington , DC

Jews United for Justice
Washington, DC

Joint Center Health Policy Institute
Washington, DC

Legislative Counsel to Honorable John Conyers Jr., Congressman 14th. District of MI
Washington, DC

Medgar Evers College, CUNY -
VP for Assessment, Planning & Accountability
Brooklyn, NY

Metropolitan Washington Council, AFL-CIO
Washington, DC

National Association of Latino Elected Officials
Los Angeles, CA

National Association of Chronic Disease Directors
East Lansing, MI

National Center for Healthy Housing
Columbia, MD

WE ACT for Environmental Justice
New York, NY

National Community Committee (NCC)
c/o Faith Access to Community Economic Development
Flint, MI

**National Community
Committee (NCC)**
c/o UK Prevention Research
Center
Hazard, KY

**National Community
Committee (NCC) Northeast
Region c/o Oral Health
Foundation**
Boston, MA

**National Conference for
Community and Justice**
New York, NY

**National Congress of
American Indians**
Washington, DC

National Council of Churches
New York, NY

**National Health Law Program,
Inc.**
Washington, DC

**National Healthy Babies
Healthy Mothers Coalition**
Alexandria, VA

**National Hispanic Medical
Association**
Washington, DC

National Indian Health Board
Washington , DC

**National Latina Institute for
Reproductive Health**
New York, NY

National Medical Association
Washington, DC

National Minority AIDS Council
Washington, DC

**National Minority Health
Month Foundation**
Washington, DC

**National Women's Law Center
- Health & Reporductive
Rights Program**
Washington, DC

**NHGRI
National Insititutes of Health**
Bethesda, MD

**Physicians for Social
Responsibility**
Washington, DC

**Poverty & Race Research
Action Council (PRRAC)**
Washington, DC

**Southeast Asia Resource
Action Center**
Washington, DC

**Summit Health Inst. for
Research & Education, Inc.**
Washington, DC

The Opportunity Agenda
Washington , DC

The Praxis Project
Washington, DC

Barbara Baylor
United Church of Christ

**United Methodist General
Board of Church & Society**
Washington, DC

**United Methodist General
Board of Church & Society**
Washington, DC

University of Michigan
Ann Arbor, MI

**Office of U.S. Representative
Edolphus Towns 10th
Congressional District of New
York**
Washington, DC

Attachment 5 – Agenda

**The Genetics Equity Network:
Achieving Equity in Genetics Policy through Diversity in Decision Making**

Agenda

8:30 a.m. – 9:00 a.m. Continental Breakfast/ Registration

9:00 a.m. – 12:00 p.m. Making Connections, Applying Concepts

Panel discussion and dialogue moderated by David Camp

9:00 a.m. – 9:15 a.m. Welcome and introductions

9:15 a.m. – 10:00 a.m. **Sharon Kardia**

Associate Professor, University of Michigan School of
Public Health

How is genetics related to health disparities?

10:00 a.m. – 10:45 a.m. **Aranthan Jones ("AJ")**

Chief of Staff for Congressman William Jefferson
(Louisiana, District 2)

*What are current practices in genetics policy decision-
making that would benefit from diversity to reduce
disparities? Why does it matter?*

10:45 a.m. – 11:00 a.m. Break

11:00 a.m. – 11:45 a.m. **Makani Themba-Nixon**

Executive Director, The Praxis Project

Why do we need to engage our communities?

11:45 a.m. – 12:00 p.m. Debrief

12:00 p.m. – 12:45 p.m. Lunch

12:45 p.m. – 3:30 p.m.

Moving Toward Action

1:00 p.m. – 1:30 p.m. Identifying and answering critical questions for the Network (Small group discussion – Questions TBD)

1:30 p.m. – 2:00 p.m. Debrief

2:00 p.m. – 2:15 p.m. Break

2:15 p.m. – 2:35 p.m.

Building a Network

How can we create supportive connections within the Genetics Equity Network to maintain a sustainable and diverse partnership?

What kinds of activities do you envision as central to the Network?

How can we position the strength of our relationships to secure funds and other resources to increase, and then sustain diversity at the genetics policy tables?

2:35 p.m. – 3:05 p.m. Debrief

3:05 p.m. – 3:30 p.m. Conclusion

3:30 p.m. Launching a network

Reception – Website Demonstration

Attachment 6 – Biographies

Sharon L. R. Kardia

Sharon is an Associate Professor of Epidemiology at the University of Michigan. She is Director of the Public Health Genetics Program, Co-Director of the Michigan Center for Genomics and Public Health, and Co-Director of the Life Sciences & Society Program housed in the University of Michigan School of Public Health.

Sharon's main research interests are in the genomic epidemiology of cardiovascular disease and its risk factors. She is particularly interested in gene-environment, gene-gene interactions, and in modeling complex relationships between genetic variation, environmental variation, and risk of common chronic diseases. She has served on three National Academy of Sciences Committees examining the technical and social challenges of conducting genetics research that benefits the public good. She is also launching an ambitious Genetics, Ethics, and Meaning Initiative (GEMINI) in partnership with community to couple genetic information with experiential and spiritual wisdom through story, case histories, and technological innovation.

Sharon received her doctoral degree in human genetics from the University of Michigan, was a post-doctoral fellow in the Department of Microbiology and Immunology and continued post-doctoral work in the Department of Human Genetics. She joined the faculty of the University of Michigan School of Public Health in 1998.

Aranthan Steve Jones II

“AJ”

Aranthan Steve Jones II or “AJ,” is the Chief of Staff for Congressman William Jefferson of the 2nd-District of Louisiana. In this capacity AJ is responsible for crafting, directing and advising on Health and Human Resource policies under the jurisdiction of the Ways and Means Committee. AJ also serves as the Congressman’s advisor on labor, global health, public health preparedness, and director of intergovernmental affairs for all Hurricane Katrina federal and state legislative initiatives.

Prior to joining Congressman Jefferson’s office; AJ was the health director policy for the Congressional Black Caucus Health Braintrust (CBC-HBT) chaired by Congresswoman Donna M. Christensen of the Virgin Islands. In this capacity he served as the health policy advisor for the Congressional Black Caucus and directed their policy positions on access to care and health, public health, children health, health education, and health disparity elimination. In addition, he served as a lead health advisor to the Select Committee on Homeland Security’s Subcommittee for Preparedness and Response. To date, AJ remains a member of the CBC-HBT Ad-Hoc advisory committee.

AJ has been noted in numerous health conferences and periodicals as being the “point-man” in regards to health disparity elimination policy and public health policy. This reputation lead to AJ being appointed as a lead health advisor for the Congressional Minority Caucuses (which represent over 150 Congress members and is comprised of the Congressional Black, Hispanic, Native American and Asian Pacific American Caucus), Congressional Black Caucus International HIV/AIDS Taskforce, Congressional Bicameral HIV/AIDS Taskforce, and congressional advisor for minority health disparities on the John F. Kerry and John Edwards Presidential campaign of 2004. He also served as an advisor to over 11 Congressional Member Organizations.

Makani Themba-Nixon

Makani Themba-Nixon is Executive Director of The Praxis Project, a nonprofit organization helping communities use media and policy advocacy to advance health equity and justice. Current projects include Policy Advocacy on Tobacco and Health (PATH) — a Robert Wood Johnson Foundation Initiative to build tobacco control policy advocacy in communities of color; as well as numerous tools and resources that help people translate local problems into progressive, effective policy initiatives.

Makani was previously director of the Transnational Racial Justice Initiative (TRJI), an international project to build capacity among advocates to more effectively address structural racism and leverage tools and best practices from around the world. While at TRJI, she co-authored and edited a "shadow report" on institutional racism.

Prior to that she directed the Grass Roots Innovative Policy Program (GRIPP) a national project to build capacity among local organizing groups to more effectively engage in media and policy advocacy to address institutional racism in welfare and public education. She was a staffer for the California State Legislature, served as media director for the Southern Christian Leadership Conference/Los Angeles, and worked five years for the Marin Institute for the Prevention of Alcohol and Other Drug Problems, including three years as director of its Center for Media and Policy Analysis.

Attachment 7 – Evaluation Report

Achieving Equity in Genetics Policy through Diversity in Decision Making
 October 5, 2006
EVALUATION
N=18

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Overall, I enjoyed the workshop.	12	7	0	0	0
I would attend another workshop on similar topics.	10	9	0	0	0
I consider myself part of the Genetics Equity Network.	7	9	3	0	0

What did you like best about today's workshop?

Presentations & Discussions.

Interactive nature of group. Wonderful & rich ideas. Common ground. Honest, open dialogue. Open to challenge concepts/ideas.

I liked the interactive structure of the sessions.

Sharon Kardia's presentation.

Networking with other people regarding important issues as in this workshop.

The new perspectives I gained on genetics and it's uses and misuses.

Information provided – ability to be reflective.

The energy and modesty of the participants. By and large, very down to earth folks with a common commitment.

Key note speaker presentation was very educational and informative.

The active discussion. I enjoyed it all.

The small groups.

Learning about the topic and interacting with such diverse stakeholders.

Enjoyed Dr. Kardia's presentation greatly. Well spoken on "general public" and friendly. I liked the overall information shared and ability to network.

Genetics introduction by Sharon.

I got lots of insights on new topic.

Learning about genetics policy.

Everything.

Presentation by Sharon Kardia. Excellent job of summarizing many complicated issues very thoroughly. I also enjoyed meeting others engaged on this issue.

What did you like least about today's workshop?

Delayed beginning put us behind schedule.

Needed 101 Genetics workshop before workshop on policy.

Took longer than advertised.

Time could have been a bit better planned. Some topics did not seem to reach full closure.

The abrupt facilitation. Kinder/gentler exchange may have yielded more from the group. The other item was our inability to stay on schedule.

We went over time. Discussion is great, but when people leave, it hurts discussion. End on time no matter what.

It started too late and threw off the schedule.

At times, I felt like we had too much time to discuss something. Other times we did not have enough time. Better time management.

The amount of time we ran over; no time keeper. Too many things put into one day.

Break out on how to sustain the network.

List of things to prioritize – not really prioritizable. List of objectives, tactics, activities, broad, specific. A little bit of cart before the horse.

Poor time management.

I am still not certain what the Network's primary mission is or what my responsibilities or roll in the Network will be.

What suggestions do you have for future workshops of the Genetics Equity Network?

Plan opportunities to specifically focus on identified themes.

Plan a longer workshop.

Genomics 101 & Policy 101.

Agenda of next meeting should reflect input and tasks from today.

Slightly larger venue with more parking. More interfaith and political involvement. Inclusion of the financial services industry, as their work in investment of pharmaceutical companies, managing local and state pension funds ties directly to social responsible investment.

Keep the high degree of interaction.

Really define the network – what it is, who's involved, what are the goals, etc.

More concentrated and specific focus on particular problems related to building the network internally.

An annual meeting with same or more groups to discuss progress of network. Maybe a 2-3 day conference.

Discussion of implications of genetics perspective for universal health care.

Facilitator took too much time. We had lots of our own questions and comments.

Please respect people's time and stay on schedule. Maybe mix up presentations and discussions to vary the day.

Additional Comments:

This definitely should continue.

Thank you for a great workshop.

Keep up the excellent work.

Food, process, arrangements and content were all good!

Thank you for the invitation. I look forward to "next steps".

Lunch was good; breakfast too.

Great day, learned a lot, met wonderful people doing great work.

Please email Dr. Kardia's presentation to all participants and facilitators.

Great group of stakeholders here, but there seem to be some important groups missing. Is there a way to suggest members?

Attachment 8 – Group discussions notes

Small-group discussions

1. **Building a Network:** Lessons from other networks – what works? What doesn't work?

What works?

- Smaller coalition but larger networks
- Fuzzy institutions
- Understanding each person's goal in the coalition
- Lines of convergence of urgency
-
- Common broad goals- fuzzy institution
- Small coalitions within large network
 - Network=resources (knowledge, access, experience, etc)
- Action plans- defined response
-
- Respect individuality while staying focused on common goals
- Know your team and what everyone is capable of
- Encouraging everyone's participation so everyone can feel a sense of ownership
- Creatively and efficiently using all resources (e.g. technology)
- Focus on the genetics in a way that avoids the natural tendencies to reinforce inequalities
-
- Invite all stakeholders to keep them informed (quarterly face-to-face)
- Conference calls
- Have listserv
- Listen and confirm "message"
- Maintain affability despite disagreement
- Maintaining a funding stream
- Have timelines
- Need an expert on issues
- Keep momentum
- Shared leadership
- Regular communications
- Clear reminders
- Clear "deliverables"
- Team approach
- Know people's strengths
-
- Clear goals/mission
 - Focus on the common issues
- Inclusive & diverse
- Effective communication system
 - Develop process for open dialogue about changes in the group
 - Learn from each other- discuss emerging issues from various perspectives
- Strong shared leadership
-
- Who else should be at the table?

- Youth
- Native Americans
- Women's groups
- Hold educational forums to the knowledge base
- Develop principles document
- Develop action plan (all participate)
- Develop listserv to communicate back and forth
- Work to get identified as a reliable resource on capitol hill
- Strike a balance
- Choose winnable issues
- Spend time building trust (build relationships, egos at door, etc → ongoing process)
- Reevaluate consistently (process evaluation)
- Do a power analysis
- Articulate clear and concise mission & principles
- Clarity of purpose and respectful engagement
- Use both head and heart
- Be focused and proactive
- Anticipate and plan for success

- Coordinator of the group (paid staff)
- Identification of all members of the group
- Principles of collaboration/decision making
- Legislatures understanding of group's purpose
 - Done at local and national levels
- Train academic and community partners to advocate
- Educating legislatures
- Identity issues
- funding

What doesn't work? (What are the well-intentioned traps?)

- Picking the wrong goals, strategies
- Not deviant goals
- Not all primary choices may be appreciated
- Relying a lot on online technologies
- Talk > listen

- Avoid single issues/alienating members
- Talk > listen

- In-fighting on territorial battles
- Misusing resources (funds, technology)
- Avoid the tendency to work on projects that have already been done
- Think beyond the norm when bringing on stakeholders
 - Be flexible in the selection of stakeholders for specific issues
- Find ways to promote community education to stimulate community constituency

- Being overcommitted
- Too much talk , less action
- Too few people engaged
- Not enough time to share their experience

- Not every voice is heard and/or respected
- Not having any guidelines
- Not having a consensus
- Boredom
- Confusing ideas into action
- Turning problems into solutions
-
- Don't focus on or get stuck on special interest issues
- Don't avoid controversy/confrontation
- Don't exclude non-traditional partners
-
- Keep to consensus document
- Sign on better (don't sign on if don't agree- avoids conflict)
- Follow process even if miss the deadline
- Need rules of engagement, guidelines
- Not recruiting new members (fresh ideas, energy)
- Don't compete with other members, share resources
- Not staying in touch
- Overburdening a few people
- Don't bit off more than you can chew (resources)
-
- Reactive/defensive
- Let others label/name the group
 - Be careful in picking a name
- No individual/separate agenda
- Competition for funding between group and individual members
- Lose sight of the mission
-
- Do not assume technology is the only form of communication (it can limit engagement)
- Forgetting that everyone doesn't have technology
- Using a style that is dismissive of less popular issues
- Burnout (taking too much on)
- Worthy but unrealistic goals

2. What should this Network do?

Message framing group

- Target populations
- Tell the human story
 - Different themes
 - Different groups
- Policy Council
- Community roundtable
- Develop principles that embodies the values of the group
- Preventative health emphasis
- Frame the message in more than one way
- 2-3 times a year a 500 word article to each organization's newsletter
 - Member of that organization responds to article, explaining how network relates to that organizations goals

- Send response to network for distribution through listserve/newsletter
- Strong communication that seeks to build involvement
 - Listserve
 - Mailings
 - Newsletter
- A listing/menu for organizations to select other groups that a commonality exists, to work on an individual task
 - Similar goals, missions
 - Let each other know about resources and capabilities

Participation in genetic research group

- Think past, present, future
 - Where it's been, what's going on now, where we can and want to go
- Getting all committee members involved the whole way
- Getting useful information- not doing research for the sake of research.
- Getting info that will aid in the community educations
- Goal: get community at the table to get us in the community as difference makers
- Be involved after
 - Who is the research for
 - Who has access to it
- Make research understandable for everyone
 - So pitfalls are understood
 - Benefits are known
- Network being hands on
- Understand the grant and understand how we stay in compliance
- Get community involved with research not just make them the research
- Make the community a driver eventually in where the research should go
- Diversify revenue streams, not just government funds
- Eventually moving from ad-hoc to a legitimate organization

Genetics Education group

- Coalitions depend on educated communities and networks
 - Reasons for educations
 - Impact expected
 - Insurance, patients etc
 - Laying out issues people can relate to
- Informed consent
- Modes of education
 - Newspapers, high schools, PSAs
- Basic principles of education- genetics 101
- Environment and genes
- Privacy and confidentiality
 - Rights, duties towards education
- Identification of genetic resources
 - www, peer reviewed resources, public libraries, community outreach thru PSAa, brochures, focus groups
 - public organizations such as churches, ma-baby bus, unions, social workers, nurses, common recreational places

- Re-evaluating goals for the target population
 - Identifying target audiences
 - Bang for buck- biggest target audiences for education
- HIPPA rights
- Developing partnerships
 - Financial gains
 - Using them as resources
- Testing and evaluating education materials
- Analyzing the level of education provided to target group

3. How to Create a Sustainable Network

- Web page – e-mail to make sure that network
- Listserv
- “regular old mail”
- Creation of a 500 word article put out 2-3 times a year going to each organizations' newsletter educating and updating on goals/actions of network – with response by a member of the org – with response on how the network relates to the organization's goals and mission
- Menu for the organizations to go to find out what they're interested in – let each individual org to know what resources/capabilities the other orgs have

Attachment 9 – Website

Homepage

The screenshot shows the homepage of the Genetics Equity Network (GenENet) in a Mozilla Firefox browser window. The browser's address bar displays <http://genetwork.org/>. The page features a header with the title "Genetics Equity Network" and a main banner with the text "Achieving Equity in Genetics Policy through Diversity in Decision Making". Below the banner, there is a navigation menu with links for "ABOUT US", "GENETICS", "POLICY", "INTERACTIVE", and "CONTACT US".

The main content area is divided into several sections:

- Sign-up:** A section on the left encourages users to sign up for notifications. It includes a form with fields for "Name" and "Email address", and a "Submit" button.
- About The Genetics Equity Network (GenENet):** A central section with a heading and a paragraph: "A new era of healthcare influenced by the explosion of genetic knowledge and technology is emerging. Scientists are developing medicines that are tailored to an individual's genetic make-up; genetic tests are being used to determine one's chances of developing certain diseases; and researchers are finding ways to customize diets based on a person's genetic profile and lifestyle. These are just some examples of the practical applications of genetic research that evoke both excitement and concern about its impact on the health of our society." Below this text is a list of three questions:
 - What if these innovations are not available to everyone?
 - Will research and development lead to worsening health disparities through exclusion?
 - How will genomic information be managed?
 - Who decides what and how to study genetics?
- Issue Areas:** A section on the right titled "ISSUE AREAS" with a list of topics:
 - CRIMINAL JUSTICE
 - ACCESS TO HEALTH
 - RACE-BASED MEDICINE
 - RESEARCH
 - EDUCATION & THE DIGITAL DIVIDE
- What can you do to participate?:** A section at the bottom right with the heading "Join the Genetic Equity Network" and a paragraph: "The Genetics Equity Network (GenENet) is an international, interdisciplinary organization for genetic research and development and education of genetic research and development related to genetic equity in the biomedical research community. GenENet will have an advisory group and a steering committee to help in shaping genetic equity."

At the bottom of the page, there is a small text: "Transferring data from dh6370-u24.beza.net..."

<http://geneticsequitynetwork.org>

Attachment 10 – Final Budget

Item	Rationale		Amount
Jody Platt	Conference planning support staff*		6,914
Conference Calls	Eight conference calls to plan before and debrief after the event		960
Publicity/ Advertising	Postage, printing, materials for two sets of mailings		604
Program Materials	Binders, handouts, and postage		940
Travel	Travel and accommodations for 11 individuals (selected invitees, directors, and staff)		3,094
Audio/Visual	Recording of workshop		701
Catering	Refreshments during workshop		1,269
Speakers Fees	Honorarium for speaker's presentation and attendance		500
Post-event mailing	Post-event mailing		20
		TOTAL	15,000

* 15% of salary